

## EQUITABLE ACCESS TO PALLIATIVE CARE FOR ALL CANADIANS

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## Recommendations

Pallium Canada recommends that the federal government invest in a five-year program to ensure equitable access to effective, timely and appropriate palliative care services that respect the wishes of those with a life-limiting illness regardless of geography, language, or socio-economic status by supporting the following three initiatives that will serve to transform Canada's health care system:

1. In a cooperative arrangement between the private sector and the federal government, conduct a national campaign that brings palliative care out of the shadows by increasing health care provider and public awareness, literacy and engagement that will prompt dialogue, tackle stigma, highlight areas needing improvement and place palliative care higher on the national health care agenda.
2. Capitalize on the inherent desire for Canadians to assist patients and families by building and supporting community capacity through a national practice hub that identifies and leverages a community's inherent strengths and resources to provide greater care and alleviate pressure on health care systems and caregivers.
3. A national accountability engine that leverages data and research from publicly accessible sources to provide comparative benchmarks, highlight and recognize examples of success, identify gaps to action, promote knowledge transfer and improve health outcomes.

## Background

Canada is facing a national health care crisis. In addition to the increasing cost of new technologies and medications, from 2010 to 2036, the seniors' share of Canada's population will increase from 15% to more than 25%, placing greater pressure on health care services and budgets. Chronic illnesses are increasing, and more Canadians are experiencing multiple chronic conditions, leading to poorer quality of life and increased resource utilization.

There is a large and growing body of evidence that palliative care, especially when initiated earlier alongside treatments to control these illnesses, results in better quality of life for patients and better treatment decisions, including more judicious use of new technologies and medications.

Despite the benefits imparted by palliative care, many Canadians never get to benefit from it, or receive it too late. Multiple educational, financial and systemic barriers prevent equitable access to palliative care for far too many people; it is estimated that only 15% to 30% of Canadians have access to palliative care services.<sup>1</sup>

Underserved populations including those in long term care homes, refugees, LGBTQIA+, incarcerated and ex-offenders, people living with disabilities, veterans, and homeless people continue to report even higher challenges with accessing palliative care and require additional attention.

Canadians living in rural and remote communities and Indigenous peoples also experience challenges achieving equitable access to health care services<sup>2</sup>, including palliative care. Canada's official language

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<sup>1</sup> The Way Forward: A roadmap for an integrated palliative care approach to care. CHPCA 2015.

<sup>2</sup> College of Family Physicians of Canada, Society of Rural Physicians of Canada. *The Rural Road Map for Action: The Canadian Collaborative Taskforce*. 2017

minorities' needs are often not considered in health care planning. There is a need to integrate cultural competence to address the needs of new Canadians that fits with constitutional principles of equity and respect for minorities.<sup>3</sup>

While the federal government has shown leadership in engaging with P/Ts with an \$11 billion investment targeting home and community care, palliative care funding allocations have largely gone unaccounted for. There remains no financial commitment to support the implementation of the new Framework on Palliative Care.

Palliative care will touch every single Canadian and therefore must be seen as being everyone's business. Canadians expect nothing less and this right is supported by the Canada Health Act which calls for continued access to quality health care without financial or other barriers.

Investments must be made in key foundational principles articulated within the Framework including educating and mobilizing Canadians to play an active role in supporting patients and families while ensuring accountability systems are in place to measure progress.

### **Proposed Solutions**

#### **1. A national integrated palliative care awareness and engagement campaign**

Loss and death are part of life, yet the current single-minded focus on cure and our fear of dying, create barriers to holistic, person-centred care and often results in inappropriate use of resources.<sup>4</sup> The conversation around living with disease, dying, death, and bereavement needs to be normalized.

Shifting mindsets and attitudes among health care professionals through education is critical as are culture-shifting efforts in workplaces. This underscores the need for an integrated campaign that goes beyond simple "awareness raising" to actionable and achievable calls-to-action that will lead people to do something they have not done before.<sup>5</sup>

An action-oriented national campaign would secure the backing of the private sector and have broader reach than current piecemeal initiatives. As a first step, it would ask two distinct audiences—the public and health care professionals—to take a specific action in support of palliative care. For the public, actions may include supporting someone with a life-limiting illness, or a caregiver. Health care professionals will be encouraged to become educated in the palliative care approach. Both audiences would then be directed to existing resources to deepen their commitment.

Such a campaign need not be anchored in expensive mass media advertising alone. Decades of evidence-based global research suggest the most cost-effective ways of reducing the stigma associated with mental illness is through contact-based education—the power of positive personal storytelling of lived experiences. This intervention can be powerfully leveraged, especially through social media, to showcase the unique needs of the aforementioned underserved groups.

The financial burden for this initiative should not lie solely on the shoulders of the federal government. Many examples of private sector investment in public health issues exist (e.g. SunLife and diabetes,

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<sup>3</sup> QELCCC Blueprint for Action

<sup>4</sup> The Way Forward: A roadmap for an integrated palliative approach to care, 2015

<sup>5</sup> Stanford Social Innovation Review, Stop Raising Awareness Already by Christiano and Neimand, 2017

Bell's Let's Talk and mental health). These can be structured using creative funding mechanisms that leverage private funding and tie government investment to key campaign outcomes (e.g., number of trained professionals on the palliative care approach) such as PHAC's support of the hypertension reduction campaign with corporate partners Loblaw's/Shoppers Drug Mart, CAA, and Deloitte.

To truly effect change in perceptions, attitudes and behaviours towards palliative care, a national multifaceted, integrated campaign is required. This approach has been successful to curb smoking rates, decrease HIV infection rates, and change attitudes towards mental health.

## 2. Building community capacity through a national best practice hub

Inherent in Canada's character is an innate desire by its citizens to help those in need. In community-based palliative care, friends and family members play an essential role in home care. In fact, regardless of recent increases in home care investments, home care is often not possible without support from family or friends.<sup>6</sup>

To respond to the need for more community assistance, over 20 Compassionate Communities have been established across Canada which serve to empower individuals to provide important physical, emotional, social, spiritual and practical support to patients, families and caregivers.

Although a few provinces have developed initiatives to provide mentorship and support to these fledgling groups, most are left to figure things out on their own. Most have limited capacity to connect with each other, network or share best practices and are looking for high quality support to accomplish their objectives.

The development of a national best practice hub would allow community groups to sample best practice content and get ideas on how to address common challenges (e.g., funding, sustainability). Content on the hub will be designed for self-study and self-evaluation and will include articles, tools, guides and interactive surveys. This content and delivery approach break processes down into easily digestible steps, and its methods can be followed/adapted by communities of any size. Ongoing support is provided by professionals with extensive practical experience who are exemplars in their field.

The national hub will take an internationally recognized approach called "Asset-Based Community Development".<sup>7</sup> This approach focuses on identifying, leveraging and connecting the current strengths and resources that are already present in communities to enable its citizens to provide more effective support to those patients and families dealing with a life-limiting illness. This approach has shown that communities are more successful at addressing complex public health issues in a sustainable way because they harness the knowledge and strengths of diverse perspectives that already exist within their communities. Their reliance on outside funding, expertise and supports focuses on filling gaps in their 'assets' that are important (e.g., clinical expertise, event space) but not foundational to their work.

To support the national hub, partnerships with corporate and philanthropic organizations will be pursued to raise awareness and grow a sustainable base of financial support for Canada's growing Compassionate Community movement, with a target to match a federal government investment 1:1 over the term of the agreement. This partnership outreach will build upon growing trends in community

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<sup>6</sup> Access to Palliative Care in Canada, CIHI, 2018

<sup>7</sup> <http://www.deepeningcommunity.org/abcd-canada-home>

granting towards social innovation and systems-change granting models. The national hub will provide a platform for key resources, supports and networking to empower each Compassionate Community to develop their own local plan for sustainability.

In 5 years, this initiative aims to create a national best practice hub that supports the viability and ongoing sustainability of the existing network of 20 Compassionate Communities while helping to support the creation of additional Communities in service to rural and remote, Indigenous, veterans, new immigrants and language minority communities, to name a few. This investment in sustaining and growing community capacity and volunteer engagement is essential to the success of the government's existing investments in home and community care, reducing the palliative care burden on the health care system, and supporting patients' desire to die at home.

### 3. Creating Canada's first national palliative care accountability system—A Canadian Palliative Care Atlas

In many countries, large-scale, national evaluations of service availability, in the form of service atlases, have proven to be very effective change agents. These atlases highlight areas of excellence that are ready for spread, identify opportunities for improvement across jurisdictions, and help identify information gaps related to monitoring progress and accountability.

For example, a major barrier in Canada is inadequate integration of palliative care in the curricula of medical and nursing schools, residency programs and in other allied health professions. Canada would benefit from a large-scale mapping of palliative care content, models and resources across different schools, colleges and programs to identify excellence and best practices and spread these to where gaps exist.

No such Atlas exists in Canada. A Canadian Palliative Care Atlas, developed by a multi-partner and multi-sectorial research team, would map out each region in each province/territory and subsequently be leveraged to spread and scale up excellence. The Atlas will provide data and information for policy makers, industry leaders, care providers and everyday Canadians across the many regional, provincial, territorial and federal jurisdictions across Canada.

Similar to experiences in other countries, through this collaborative work, and in concert with the national awareness campaign, increased dialogue will be generated on the current progress of palliative care development across the country, and its impact on the delivery of care.

The Atlas will be an outstanding example of a collaborative effort to position palliative care higher in F/P/T health agendas, provide the data needed to make informed budget choices, and be an excellent tool to generate greater support to ultimately provide more effective, efficient and compassionate palliative care to more Canadians.

## **Conclusion**

Equitable access to palliative care remains elusive for the majority of Canadians, and for our most underserved populations, it adds to an already heavy burden. The strategies discussed above represent the fundamental building blocks that are needed to address some of the disparities that exist. With the growing need, so too is the value of a government investment to help transform palliative care in

Canada by catalyzing a social movement, building community capacity and ensuring that accountability governs how palliative care priorities are established.